

Testimony before the Appropriations Committee

DSS Budget Hearing

February 18, 2009

Good afternoon/evening. My name is Ray Veazie and I am from Norwich, CT. I am here today to testify about the effect of the Medicaid spend down on my healthcare.

I struggled to learn in school and in the community as a child and young adult. When I was 19, I was in a motorcycle accident resulting in traumatic brain injury. After rehabilitation, I always worked a full-time job and paid into the social security system which I expected to be there when I needed it. I have always had good jobs. It took me longer to learn than most people, but once I learned the job I had it down to a science. My last job involved making airplane engine parts which I did until I couldn't work any longer – I could no longer lift the heavy parts as required by the job. Since then I have been unable to find a job.

I currently receive \$1,025.00 per month in Social Security Disability. After paying all of my monthly bills which includes rent, utilities, car insurance, car taxes, gas, and car maintenance, I have approximately \$200.00 to get through the month. With this \$200.00 I need to buy food. I receive Food Stamp assistance, but this only covers 2/3 of my monthly food needs. I also need to purchase toiletries, clothes, and other necessities.

Every six month, I am subject to a "spend down" because I am determined to have too much income (\$1,025.00 per month). My "spend down" is \$2,000.00. This means I need to come up with \$2,000.00 worth of medical bills in order to have Medicaid insurance. My monthly medication costs \$708.00. I am unable to get my medication when I am on a spend down. I do have Medicare Part D, but the medications I need are not on the approved list. I have tried other medications that are on the list, but they do not work for me. My doctor gives me samples, but they only last a few days. My doctor has tried various programs to get discounted medications from the pharmaceutical companies without success. What's the point of going through all that treatment only to end up back at square one because I cannot afford the medication I need. Before I got into treatment, I self-medicated with drugs and alcohol which led to crime which led to jail and thoughts of suicide. I don't wish that on my worst enemy. I don't want to go down that road again.

When I go without my medications, my comprehension and mood are greatly affected. I also have traumatic brain injury and am supposed to take anti-seizure medications, but have had the same problems with access. I have had seizures which is life-threatening and scary. I know

PLEASE RESTORE FUNDING FOR INDEPENDENT LIVING CENTERS

Richard Suckau, 281 Hamilton Ave., #405, Norwich, CT 06360, 860-887-5931

Client and Member of the Board of the Disabilities Center of Eastern Connecticut

Madam Chairman and members of the Appropriations committee: I am Richard Suckau, from Norwich. I grew up expecting to work all my life, and did until I became disabled.

My disability is mostly invisible. You cannot tell by looking at me what kind of help I need. I live on the border of life, not disabled enough for sympathy—whatever that's worth— and not “normal” enough to work. I think of myself as normal, though I'm not really sure what that is. People like me often fall into the cracks of the system. They don't know how to help themselves, so they eat at soup kitchens, drown their sorrows, and wallow in self-pity.

Independent Living Centers, like the Disabilities Network of Eastern Connecticut (DNEC) “adopt” cases like mine. They start by offering a friendly and accepting ear, and move on to short term answers that eventually build into long term solutions. They work mostly by connecting people to resources that can meet their needs.

Independent Living Centers do not give out complicated forms that people need a law degree to read. They do not have complicated intake procedures designed to discourage people from coming back. They do not turn people away who have multiple disabilities or other complications. They accept people as they are. They provide hope and human kindness.

Independent Living Centers help people navigate the state system. They save *money* by saving *people* from being more disabled than they need to be. They know how complicated it is because all of the staff have disabilities too and all are paid from different grants. DSS uses that complicated funding structure to justify *eliminating* state funding for Independent Living Centers and admits that one or more may close. That cost is acceptable to DSS, but not to me. I can think of no better investment of—the state's money. Can you?

Thank you for your attention. Just having you listen gives me some confidence that you will do the right thing.